Building and Evaluating Cancer Registry Capacity in Moshi and Mwanza, Tanzania

Leah Zullig, PhD, MPH
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Cancer Diagnosis

- Developing Countries: 54%
- Developed Countries: 46%

Cancer Deaths

- Developing Countries: 64%
- Developed Countries: 36%
Cancer Registry Coverage

U.S. and Canada: 100%
Western Europe: 94%
Southeast Asia: 80%
Africa: 6%
South America: 4%

Implications

- Underestimate cancer incidence and mortality
- Develop reliable population-based registries
- Understand cancer trends and leverage resources

Source: International Agency for Research on Cancer
Tanzania

Mwanza

Moshi

Dodoma

Dar es Salaam
Objective

**Aim 1:** Evaluate quality of existing KCMC hospital-based cancer registry

**Aim 2:** Expand data collection to include Bugando Medical Center

### Kilimanjaro Christian Medical Center

- Tertiary referral hospital
- Serves an estimated 11 million people
- Active hospital-based cancer registry began in August 2013
KCMC Cancer Registry

• Began in August 2013
• Uses CanReg5
• Contains 1,200 unique patients

Bugando Medical Center

• Serves an estimated 13 million people
• Offers pathology services, chemotherapy administration, and radiation therapy
Project Team @ Duke

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Health Services Researcher

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Medical Oncologist

Kristin Schroeder, MD
Pediatric Oncologist

Project Team @ KCMC

Venance Maro, MD
Head of Internal Medicine

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Lecturer in Community Health
Significance

Population-based cancer registries are an essential component of a fully developed cancer control program.

Assessment of KCMC’s registry now provides early opportunity to strengthen data quality.

Exchanging information between KCMC and BMC registry will allow for more comprehensive understanding of cancer burden.

Previous and Ongoing Work

- HIV-associated Malignancies Research Training Program (Bartlett)
- Medical Education Partnership Initiative (Bartlett)
- Research with Kampala Cancer Registry (Schroeder)
- Cancer Registration Training (Oresto)
KCMC Two-Phased Needs Assessment

Paper-Based Survey
June 2012
- Organizational Readiness to Change
- Organizational Needs

Semi-Structured Qualitative Interviews
March 2013
- Organizational Readiness to Change
- Perceptions about Registry Sustainability


Needs Assessment Findings

KCMC Clinicians and Administrators were **Confident** and **Committed** to Registry Implementation

Stakeholders identified **International Partners** as key ingredients for sustainability
Aim 1

Evaluate the quality of existing data in the KCMC hospital-based cancer registry

- Retrospective analysis of data collected in the KCMC registry from August 1, 2013 through December 31, 2013

Data Quality

Completeness:
Percentage of variables completed within a case

Accuracy:
Internal consistency within a registry record and medical record
Aim 1 Methods

• Sample 10% of the registry cases from first year
• Compare the electronic cancer registry case file with paper-based medical record
• Review discrepancies and adjust cancer registry
• Conduct a root cause analysis to identify possible sources of error
• Apply lessons learned for training

Aim 1 Statistical Considerations

• Pilot study
• Frequency distributions
• Cancer frequency trends compared to similar African cancer registries
### KCMC Registry Contents

<table>
<thead>
<tr>
<th><strong>Patient Information</strong></th>
<th><strong>Follow Up</strong></th>
<th><strong>Tumor</strong></th>
<th><strong>Source</strong></th>
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### Cancer Registry

- **Medical Records**
- **Major Clinical Wards**
- **Pathology Results**
Aim 1 Products

- Report to KCMC leaders
- Apply lessons learned to expansion at BMC
- Submit abstract to AORTIC annual meeting
- Prepare publishable manuscript

Aim 2

Expand data collection to include a second site, BMC, in Mwanza

- Build cancer registration capacity at BMC and collect data for 3 months as part of a feasibility study
BMC Cancer Registry

- Prospective registry
- 30-120 patients expected monthly
- Using CanReg5
KCMC-BMC Collaboration

- Weekly communication
- BMC staff visit KCMC
  - Observe registry case finding and data collection
  - Plan for BMC set-up
- KCMC staff visit BMC
  - Facilitate equipment set-up
  - Provide on-site registration training

Aim 2 Methods

- Pilot, Feasibility Study
- Program Evaluation
  - Number of cases
  - Completeness of cases
  - Cost of data collection
Aim 2 Products

- Cultivate a cancer registry team
- Develop standard operating procedures
- Report to BMC leaders of collected cases

Source: International Agency for Research on Cancer
Timeline

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<tr>
<th>2015</th>
<th>Dec</th>
<th>Jan</th>
<th>Feb</th>
<th>Mar</th>
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<td>Obtain ethics approval at Duke, KCMC, &amp; Bugando</td>
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<td>Conduct KCMC staff training based on audit findings</td>
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Research Team

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